Updating the National Newborn Screening Contingency Plan: Engaging Diverse Stakeholders and Families

Monday, March 6, 2017
4:30 PM – 5:30 PM
Learning Objectives

• Understand the purpose and benefit of newborn screening (NBS) contingency plans (CONPLAN).
• Learn about the national CONPLAN and recently revised version and new resources.
• Discuss opportunities for various stakeholders to apply the CONPLAN to their work.
• Identify opportunities for Title V, Families and others to apply contingency planning in their states.
Agenda

- Overview of the National Newborn Screening Contingency Plan (CONPLAN)
- Updates from the 2017 Revised CONPLAN
- New Resources
- Discussion: Opportunities to Use the CONPLAN in Your Work
  - Title V and Family Perspectives
Newborn Screening & Contingency Planning

- Nearly all of the 4 million infants born in the U.S. each year are screened by state NBS programs
  - More than 12,000 infants are diagnosed with detectable, treatable disorders
- Early diagnosis and treatment can help manage or prevent severe (often lifelong) consequences
- Contingency planning for an emergency helps to:
  - Ensure the availability of critical resources
  - Maintain continuity of operations
Newborn Screening & Contingency Planning, cont’d

• Ongoing interest in effective implementation of NBS systems.

• 2004 - APHL Subcommittee framework for public health labs to prepare for and respond to emergencies.

• 2005 – Hurricanes Katrina & Rita destroyed Louisiana's state public health laboratory
  • Worked with Iowa to conduct LA’s NBS

• Led to creation of regional NBS and national CONPLAN
Developing a National CONPLAN

• Newborn Screening Saves Lives Act of 2008
  • Directs CDC – with HRSA and State Agencies – to develop a national NBS contingency plan for use by a state, region, or consortia of states in the event of a public health emergency.

• 2008 – CDC/HRSA Workshop
  • Federal partners; State public health programs (including newborn screening programs, state labs, maternal child health programs); state emergency preparedness programs; and clinicians

• 2010 – CONPLAN published
Current Efforts: Revising the CONPLAN

• In 2015, AMCHP partnered with CDC, HRSA, APHL, and expert stakeholders to update the national NBS CONPLAN.

• Aims were to:
  • Address gaps in laboratory, clinical and long-term follow-up;
  • Add point-of-care screenings for hearing and critical congenital heart defects; and
  • Strengthen emphasis on family engagement.
Advisory Committee Members:

- Newborn screening programs
- Public Health Labs
- Regional Collaboratives
- Family Voices
- Newborn screening HIT
- Metabolic Specialists
- Title V

- AAP
- AMCHP
- APHL
- ASTHO
- CDC
- HRSA
- March of Dimes
- NACCHO
CONPLAN Update Process

• Advisory Committee calls and in-person working meeting
• Public Comment Survey (Winter 2015/16)
• Subcommittee revisions and resource development
• Submission of revision recommendations to federal partners
• CDC and HRSA review and publication
Overview of Revisions

• Changes to Strategic Objectives:
  • New Communications objective added
  • Communications & Family Education objectives were moved to top to reflect priority
  • Long-term follow-up language added

• Expanded section on Legal Issues

• Incorporation of:
  • Emergency Medical Assistance Compact (EMAC)
  • Early Hearing Detection & Intervention (EHDI)
  • Critical Congenital Heart Disease (CCHD)
New Strategic Objectives

1. Ensure ongoing communication to families, providers, birth facilities, and agency staff is ensured.
2. Educate families about newborn screening.
3. Conduct screenings; collect and transport specimens.
4. Ship specimens to the designated newborn screening laboratory site.
5. Process specimens.
6. Report screening results to physicians and families.
7. Perform diagnostic testing for infants with urgent positive screening results.
8. Ensure availability of treatment and management resources.
9. Carry out other activities determined appropriate by the HHS Secretary.
Updates and New Resources

- Updated “Responsibilities Matrix”
- New Appendices Created:
  - NBS Flowchart
  - NBS Contingency Planning Checklist and Tips
  - Resource List, including state examples and templates
Appendix B: Newborn Screening Contingency Planning Checklist
This checklist includes the strategic objectives, operational objectives and major supporting actions that should be considered when planning and preparing for newborn screening contingency operations. It is important to note that not all emergency situations are the same and not all of the identified items may be needed. Additionally, there may be other items and issues that will need to be addressed that are not included in this plan.

### Strategic Objective 1: Ongoing communication to families, providers, birth facilities, and agency staff is ensured

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Resources / Tips</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>External</strong></td>
<td>Ensure all stakeholders are aware of the existence of a contingency plan. Consider social media as an internal communication mechanism.</td>
</tr>
<tr>
<td>Establish relationships with and identify contact information for established relationships with:</td>
<td></td>
</tr>
<tr>
<td>Birth facilities – nursery and laboratory</td>
<td></td>
</tr>
<tr>
<td>Known midwives</td>
<td></td>
</tr>
<tr>
<td>Local family practice and pediatrician groups</td>
<td></td>
</tr>
<tr>
<td>Appropriate specialists</td>
<td></td>
</tr>
<tr>
<td>Families already identified with a newborn screening condition</td>
<td></td>
</tr>
<tr>
<td><strong>Employ multiple communication modalities:</strong></td>
<td></td>
</tr>
<tr>
<td>Phone</td>
<td></td>
</tr>
<tr>
<td>Emergency call-back system</td>
<td></td>
</tr>
<tr>
<td>Integrate with Health Alert Network</td>
<td></td>
</tr>
<tr>
<td>Social Media (Facebook, Twitter, LinkedIn)</td>
<td></td>
</tr>
<tr>
<td>Text</td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
<tr>
<td>Family resource centers (e.g., Prenatal Care Resource Centers)</td>
<td></td>
</tr>
<tr>
<td>Radio &amp; Television</td>
<td></td>
</tr>
<tr>
<td>Program/Agency Website updates and streaming audio sessions</td>
<td></td>
</tr>
</tbody>
</table>

Provide education and training:

- Families

---

### NEWBORN SCREENING CONTINGENCY PLAN FLOWCHART

<table>
<thead>
<tr>
<th>Ongoing communication to families, providers, birth facilities, and agency staff is ensured.</th>
<th>An effective newborn screening communication network is established.</th>
<th>A plan for communications to all stakeholders during an emergency event is established.</th>
<th>Multiple communication modalities are in place and utilized.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Families are educated about newborn screening.</td>
<td>Families know about the need for newborn screening.</td>
<td>Families with newborns who are screened know how to obtain newborn screening results.</td>
<td>Families know what to do in response to newborn screening results.</td>
</tr>
</tbody>
</table>

#### Screens conducted; Specimens are collected and transported

What should be available?

- NGSP-certified blood spot collection cards
- Other materials required for blood spot collection, hearing screening and pulse oximetry CCHD
- Training on how to conduct blood spot and point of care screenings
- Training and processes on how to collect and ship dried blood spot specimens

#### Specimens shipped to designated newborn screening laboratory site within 24 hours

How do you manage missing or missing dried blood spot (DBS) specimens?

- Ensure DBS specimens to impacted labs should be redirected to appropriate labs.
- Missing and shipped DBS specimens should be recognized, and new specimen obtained.

#### Specimens are processed.

What should be secured?

- Integrity of specimens and results at all labs
- DBS specimens are processed
- Address emergency situation to preserve or restore capacity.

What decisions should be made?

- The need for additional / alternative capacity
- Appropriate internal and external stakeholders to notify
- Whether to activate back-up lab system for managing external specimens

#### Screening results reported to physicians and families.

What communication lines should be established?

- Screening/receiving laboratories, hospitals and Labs follow-up coordinator
- NBS program and physician or health care provider
- If health care provider is not available, communication between NBS program and families should occur.

What should be identified and tracked?

- All screening specimens and results.
- Infants who are not screened.

#### Diagnostic testing is performed.

What actions should be taken?

- Diagnostics testing and results returned.
- Diagnosis is established.

Results are communicated to the health care provider, family, and NBS screening program.

#### Availability of treatment and management resources is ensured.

What should be identified and confirmed for inents with diagnosis?

- Appropriate treatment, services and/or intervention
- Access to care and connection with a medical home
- Appropriate multidisciplinary services through an established medical home
- Connection to long-term follow-up program and services, if applicable

Preparedness issues are identified and addressed for NBS systems.

Implementation, maintenance, and validation of the NBS Contingency Plan are performed by HHS.
Questions?
Discussion Panel: Using the CONPLAN to strengthen collaboration in your state

• Title V Perspective
  • Johnna Watson, R.N., BSN, Program Chief, Newborn Screening and CCHD Follow-Up Program, Office of Genetics and People with Special Health Care Needs, Maryland

• Family Engagement Perspective
  • Mary Castro Summers, Patient and Family Resource Specialist, Franciscan Children’s, Brighton, Massachusetts
How can you apply contingency planning in your state/community / program?
Next Steps:

- Currently in review/clearance process with CDC & HRSA
- Aim to release by March 2017
- AMCHP Conference Workshop
  - March 6, 2017 (Kansas City, MO)
- APHL Symposium – Sept. 2017
- Dissemination plan developed with Advisory Committee
THANK YOU!

The updated CONPLAN will be posted at:

- http://www.cdc.gov
- http://www.hrsa.gov