National Newborn Screening Contingency Plan Update

ACHDNC Meeting
February 9, 2017

Kate Taft, Associate Director, Child & Adolescent Health Association of Maternal & Child Health Programs
Newborn Screening & Contingency Planning

- Nearly all infants born in the U.S. are screened by state NBS programs
  - Approx. 12,000 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, the continuity of operations and sets standards
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 take over 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 plan 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:
  • Addressing gaps in laboratory, clinical and long-term follow-up;
  • Add point-of-care screenings for hearing and critical congenital heart defects
  • Include a stronger emphasis on family engagement.

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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
- Public Comment Survey (Winter 2015/16)
- In-person working meeting
- Subcommittee revisions and resource development
- Submission of revision recommendations to federal partners
- CDC and HRSA review and publication
Overview of Revision Recommendations

- Changes to Strategic Objectives:
  - New Communications Objective added
  - Reordered: Communications & Family Education objectives were moved to the front
  - Long-term follow-up language added
- Expanded section on Legal Issues
- Incorporation of EMAC
- Incorporation of EHDI and Point of Care
New Strategic Objectives

1. Ongoing communication to families, providers, birth facilities, and agency staff is ensured.
2. Families are educated about newborn screening.
3. Screens are conducted; specimens are collected and transported.
4. Specimens are shipped to the designated newborn screening laboratory site.
5. Specimens are processed.
6. Screening results are reported to physicians and families.
7. Diagnostic testing is performed for infants with urgent positive screening results.
8. Availability of treatment and management resources is ensured.
9. Carry out other activities determined appropriate by the HHS Secretary.
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Updates and New Appendices

• 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.

<table>
<thead>
<tr>
<th>Strategic Objective 1: Ongoing communication to families, providers, birth facilities, and agency staff is ensured</th>
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<tbody>
<tr>
<td><strong>Objectives</strong></td>
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<tr>
<td>1.1 Establish an effective newborn screening communication network</td>
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NEWBORN SCREENING CONTINGENCY PLAN FLOWCHART

- **Ongoing communication to families, providers, birth facilities, and agency staff is ensured.**
  - An effective newborn screening communication network is established.
  - A plan for communications to all stakeholders during an emergency event is established.
  - Multiple communication modalities are in place and utilized.

- **Families are educated about newborn screening.**
- Families know about the need for newborn screening.
- Families know how to obtain newborn screening results.
- Families know what to do in response to newborn screening results.

- **Specimens are processed.**
  - What should be secured?
    - Integrity of specimens and records at all times.
    - Specimens sent to and received by back-up labs.
    - All DBS specimens are processed.
    - Address emergency situation to preserve or restore integrity.
  - What decisions should be made?
    - The need for additional / alternative procedures.
    - 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/recording 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 are ensured.
    - Diagnosis is established.
    - Results are communicated to the health care provider, family, and NBS screening program.

- **Availabilty of treatment and management resources is ensured.**
  - What should be identified and confirmed for infants with diagnosis?
    - Appropriate treatment, services and/or intervention.
    - Access to 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.

*Carry out other activities determined appropriate by the HHS Secretary.*

Preparedness issues are identified and addressed for NBS systems.

Implementation, maintenance, and validation of the NBS Contingency Plan are performed by HHS.
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!

ktaft@amchp.org
202-266-3056