

National Newborn Screening Contingency Plan Update

ACHDNC Meeting
February 9, 2017



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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 moved to top
 - 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

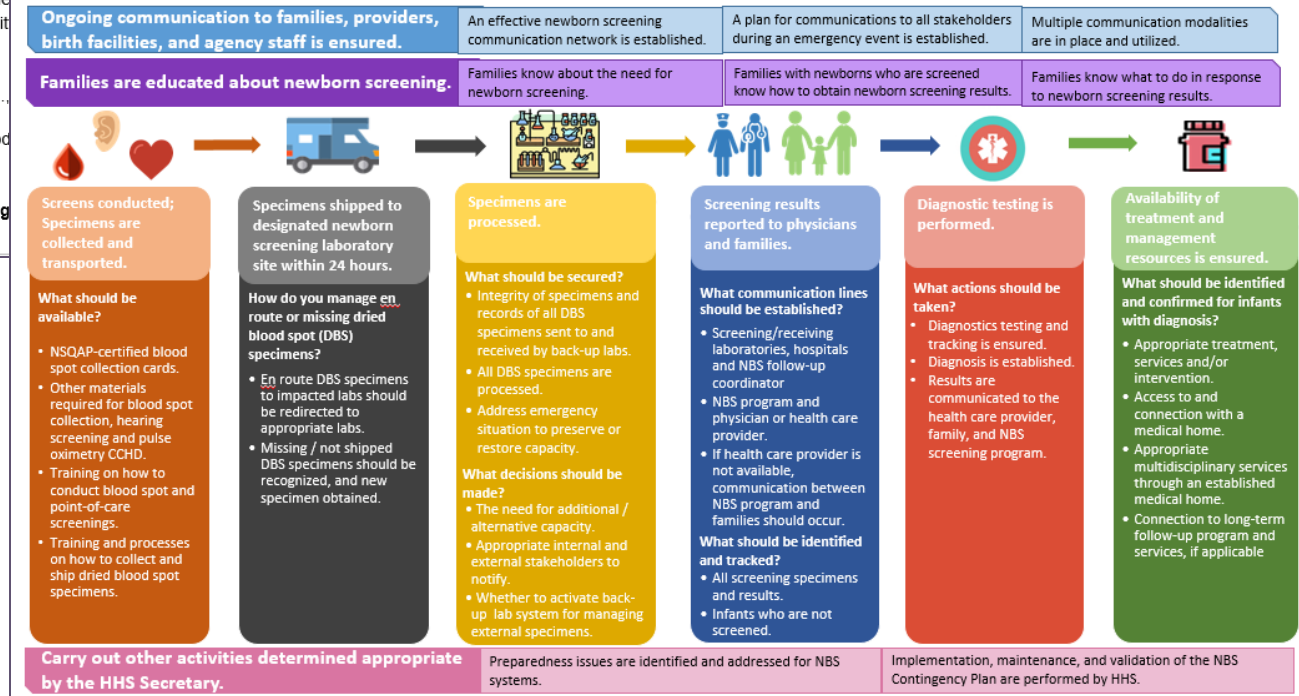
Appendix B: Newborn Screening Contingency Planning Checklist

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.

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

Objectives	Are the following activities/plans in place?	Resources / Tips
1.1 - Establish an effective newborn screening communication network	<p>External</p> <p>Establish relationships with and identify contact information for/established relationships with:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Birth facilities – nursery and laboratory <input type="checkbox"/> Known midwives <input type="checkbox"/> Local family practice and pediatrician groups <input type="checkbox"/> Appropriate specialists <input type="checkbox"/> Families already identified with a newborn screening condition <p>Employ multiple communication modalities:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Phone: <ul style="list-style-type: none"> <input type="checkbox"/> Emergency call-back system <input type="checkbox"/> Integrate with Health Alert Network <input type="checkbox"/> Social Media (Facebook, Twitter) <input type="checkbox"/> Text <input type="checkbox"/> Email <input type="checkbox"/> Family resource centers (e.g., WIC) <input type="checkbox"/> Radio & Television <input type="checkbox"/> Program/Agency Website updates <input type="checkbox"/> Streaming audio sessions <p>Provide education and training:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Families <input type="checkbox"/> Providers <input type="checkbox"/> Birth facilities <input type="checkbox"/> Agency staff 	<p>Tips:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Ensure all stakeholders are aware of the existence of a contingency plan. <input type="checkbox"/> Consider social media as an Internal communication mechanism, as appropriate.

NEWBORN SCREENING CONTINGENCY PLAN FLOWCHART



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!

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