

# National Newborn Screening Contingency Plan Update

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# 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 longterm 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	External  Establish relationships with and identify contact information for/established relationships with:  Birth facilities – nursery and laboratory Known midwives Local family practice and pediatrician groups Appropriate specialists Families already identified with a newborn screening condition  Employ multiple communication modalities: Phone:	Tips:  Ensure all stakeholders are aware of the existence of a contingency plan.  Consider social media as an Internal communication mechanism, as	
	☐ Emergency call-back sys ☐ Integrate with Health Ale ☐	EWBORN SCREENING	

#### IEWBORN 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 with newborns who are screened know how to obtain newborn screening results. Families know what to do in response to newborn screening results.











Provide education and training
Families
Families
Families
Families

Social Media (Facebook, Twit

Family resource centers (e.g.

Radio & Television
Program/Agency Website upd
Streaming audio sessions

Text Email

#### transported. What should be

available?

- NSQAP-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 en route or missing dried blood spot (DBS) specimens?

- En route DBS specimens to impacted labs should be redirected to appropriate labs.
- Missing / not shipped DBS specimens should be recognized, and new specimen obtained.

- Mhat chould be cocured?
- What should be secured?
   Integrity of specimens and
- specimens sent to and received by back-up labs.

  • All DBS specimens are
- Address emergency situation to preserve or
- What decisions should be
- alternative capacity.
   Appropriate internal and external stakeholders to notify.
- Whether to activate backup lab system for managing external specimens.

Screening results reported to physicians and families.

#### What communication lines should be established?

- Screening/receiving laboratories, hospitals and NBS 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 tracking is ensured.
- Diagnosis is established.
   Results are
- communicated to the health care provider, family, and NBS screening program.

#### 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!

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