



The Heartland NBS Back-up Testing and Quality Assurance Project

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Points to Cover

- Overview of Project
- Progress Report
- MN/MO/IA Project
- Plans for Coming Year
- Additional Resources

Project Premise

- NBS is a critical service.
- Any event which increases the time between birth and the opportunity to initiate appropriate interventions increases the baby's risk of harm.
- Contingency plans for these events are the responsibility of the NBS Program.

"Emergency NBS Backup" is simply an extension of the "NBS System"

Project Objectives

- Establish a backup contingency system to ensure uninterrupted newborn screening services throughout the Heartland Region.
- Strengthen the backup contingency system by establishing a network of states capable of providing NBS backup services to one another.

Project Challenge

- The unique testing and specimen requirements for NBS will generally mean backup laboratory testing must be sought from outside the state.
 - Differences in state NBS programs
 - Legal and liability barriers hinder agreements between states to provide emergency services

Project Elements

- Harmonization and Planning (Capability)
- EMAC (Authority)
- Functional Drills (Reliability)
- Quality Assessment: Verification and Improvement Opportunities

Last Year

- MO and IA held two 1-day functional drills
- High volume day (two week old) for drill
- Drill samples handled as routine
- Reports generated and provided to state (facility address, provider, etc.)
- Reports compared to originals to assess whether action required by follow-up
- 1,400 specimens tested in parallel

This Year

- MO and IA each held 3-day functional drill
- Two week old samples were used for drill
- Three consecutive days samples handled as routine
- Reports generated and provided to state (facility address, provider, etc.)
- Reports compared to originals to assess whether action required by follow-up
- 2,100 specimens tested in parallel

Minnesota Expansion

- NBS Backup Network is growing
- MN has joined MO and IA to ensure uninterrupted NBS services thru:
 - Harmonization and Planning (Capability)
 - EMAC (Authority)
 - Functional Drills (Reliability)
 - Quality Assessment and Improvement
 - **Formalize (Expandability)**
- Drills to be completed in Nov 2009

Next Steps

Every state in the Heartland Region will have NBS backup by June 2010

- Using plans and procedures formalized with MN:
 - MO will establish NBS backup services for KS and OK and demonstrate effectiveness through functional drills
 - IA will establish NBS backup services for AR and NE and demonstrate effectiveness through functional drills
- **Harmonization amplifies return on effort**

More Next Steps

- Strengthen NBS system by enhancing contingencies throughout all the system
 - William Perry has been working as a consultant for the Southeast NBS & Genetics Collaborative
 - Continuity of care from the perspective of the medical and nutritional **clinician**, the **diagnostic laboratorian**, and the individual patient and/or their caregiver as **customer**
 - **The NCC has made him a resource for us**

More Next Steps

- Align with national efforts
 - Information harmonization
 - Increase accessibility while enhancing security
 - Recognize buried treasures
 - Extracting KNOWLEDGE and LEARNING from data
 - Seeing the bigger picture
 - Adding our piece to create the picture

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