Emergency Backup Testing for the Louisiana Newborn Screening Program after Hurricane Katrina

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Objectives

• Describe the successful emergency provision of newborn screening for the state of Louisiana in the wake of Hurricane Katrina.

• Identify general lessons learned from this specific real life example.
Timeline

- Aug 29, 2005 (Monday): Katrina makes landfall
- Aug 30: New Orleans floods when levees breached
- Aug 31: LA PHL acknowledges need
- Sep 1: EMAC by LA, IA responds
- Sep 2: Demonstrate IA web NBS Info System
  Labor Day Weekend
- Sep 6: IA selected, finalize details
- Sep 7: LA sends first batch of specimens
- Sep 8: IA sample load triples
Can we do it?

• Wednesday Aug 31, while driving to UHL branch lab in Des Moines, received call from Dr. Gilchrist
  – Can we take on babies from LA?

• Called staff at NBS lab
  – Capacity [facilities, equipment, staff]
  – Supplies and reagents [check with vendors]
  – Heart [will require sacrifice]
  – Be ready to discuss [make recommendation]
Planning is Essential

• Clear Purpose
  – Provide newborn screen for all LA babies

• Clear Objectives
  – Test results w/o follow-up has little value
  – Time is critical

• Compelling Need
  – Birthrate predicts 1-2 affected babies per week
Can we do it? The answer.

- **Capacity**
  - New facility with ample space
  - Equipment has capacity [if extend hours and days]
  - Need more staff [retired, prior, temporary]

- **Supplies and Reagents**
  - Vendors commit all necessary

- **Heart**
  - Compelling need -- for the babies
  - Willing to make the sacrifice

- **Recommendation**
  - Let’s do it
Honest Assessment

• Must not allow devastation from Katrina to spread to Iowa
• Must be able to complete what we start
• Must meet our pre-existing commitments
• Do we have the heart?
Implementation

• Wednesday August 31, 2005
  [Make changes now, though no agreement]
• The state programs are different.
• Where are the gaps?
• How is the agreement to be activated?
• Where are we going to get the staff?
• How will we ensure follow-up?
Where are the Gaps?

• Mandated disorders
  – All done by Iowa (no CAH)
• Testing methodology
  – MS/MS: 5 disorders only
  – LA T4, IA TSH
• Policies impacting test result
  – Transfusion
  – Age at collection
Where are the Gaps?

- Day to day operations
  - Specimen transport
  - Facility list
  - Missing information
  - Rejected specimens
  - Result reporting
  - Residual specimens
  - Follow-up contacts [Dr. Copeland and IA staff]
How is the Agreement to be Activated?

- The Emergency Management Assistance Compact (EMAC)
  - EMAC, a congressionally ratified organization that provides form and structure for interstate mutual aid.
  - Through EMAC, a disaster-impacted state can request and receive assistance from other member states quickly and efficiently, resolving two key issues upfront: liability and reimbursement.
  - Agreement activated in one day.
Where are we going to get the staff?

- LA staff unavailable (location unknown)
- Call previous staff from retirement
- Call previous staff from raising kids
- Delay start of new employment
- Call current staff from other lab sections
- Call current staff from other lab locations
- Use distance data entry
- Hire temporary staff
How will we ensure follow-up?

- Iowa Newborn Screening Information System
  - Distance independent [Required by Iowa program]
  - Internet-based [Office, home, motel, basement]
  - User ID and password defined secure access
  - Patient information, results, tracking, print report, comments entered and shared by all
Lessons Learned

• It can be done
• Essential to have clear understanding of purpose and objectives
• Capacity does exist within NBS community
• EMAC provides essential structure for rapid state to state emergency agreements for NBS [not just for major catastrophe]
• Great partners, in particular PerkinElmer
Benefits

• LA is now compliant with the ACMG recommended panel of NBS disorders
  – August 2006: CAH was added and MS/MS was expanded to include all disorders
  – July 2007: CF will be added to the LA mandated NBS panel and provided by IA

• The IA NBS laboratory now operates with day and night shifts 365 day per year
Planning vs Spontaneous

- Every emergency will have its own fingerprint.
- Every emergency will require some degree of adaptive creativity.
- Although our planning, of necessity, was compressed to a couple days, it was essential.
- There is now the opportunity to establish planned procedures for reliable execution for future emergencies.
Working on two projects

- First project is minimal agreements to ensure backup now.
- Second project is to establish a system to ensure uninterrupted newborn screening services in times of emergency across the HRSA defined Heartland Region.
First Project

• Four states (IA, MI, MN, WI)
• Equivalent list of disorders
• Ensure EMAC connections are in place
• In addition to sending specimens what is needed?
Second Project

- Heartland Region
  (AR, IA, KS, MO, NE, ND, SD, OK)
- No verifiable process currently exists
- No agreed upon panel of disorders
- Dissimilarities between state programs
  - Information management related
  - Procedures, practices and policies
Second Project (con’t)

- Ensure EMAC Structures in place
- IA and MO will build backup capacity
  - Will share backup burden for each state
- Establish backup between IA and MO
- Enhance Information Management Systems
  - Multi-state
  - Multi-panel
  - Backup of data and systems
Second Project (con’t)

- Harmonization of NBS across Heartland
  - PEAS tool
  - Low hanging fruit
  - Workgroups
- Emergency Preparedness Drills
  - One day drills
  - Three day drills
  - EMAC for emergency-related exercises