

# Newborn Screening Contingency Planning

Advisory Committee on Heritable Disorders and  
Genetic Diseases in Newborns and Children

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# Background

## Incidents

- Natural Disasters
- Terrorism
- Supply Chain Issues

## APHL Response

- Central Point of Contact
- Framework for Contingency Plan

# Hurricane Katrina: The Levee Breaks



# Katrina's Immediate Impact on the Louisiana State Public Health Laboratory

- New Orleans Main Public Health Laboratory and Amite Regional Lab are out of service (no phone, water or electricity)
- Represented a 70% loss of Public Health Lab space and equipment. (100% in New Orleans and Amite)
- About 10% of New Orleans staff have checked in; most have been forced to evacuate outside of the state of Louisiana



View from Employee Entrance of the Louisiana State Office Building toward LaSalle Street on September 5, 2005.

# Why Maintain Newborn Screening Operations?

## Preventive Public Health Program

- Early identification of medical conditions
  - Collection of bloodspots 24-48 hours
- If left untreated can lead to -
  - Catastrophic health conditions
  - Mental retardation, severe disabilities or death
  - Enormous costs
    - Financial
    - Human suffering

# Framework for Newborn Screening Programs to Prepare for Disasters

- Partners
- Emergency Laboratory Testing
- Testing Materials Procurement
- Communication
- Memoranda of Understanding (MOU)

# Local Partners

- Hospitals
- Clinics
- Physicians
- Medical Association
- Hospital Associations
- Case Managers
- Homeland Security Agency

# City/State Agencies Identified

- Emergency Response Centers
  - City
  - State
- Press Offices
  - City
  - State
  - Public Health

# National Partners

- APHL
- CDC
- HRSA
- NNSGRC
- ASTHO
- Parent Advocacy Groups
- Manufacturers
- Regional Disaster Organizations

# Emergency Checklist

- Emergency Electrical Power Available
- Specimen Acquisition
- Case Management, Instruments
- Laboratory Information Management System(s)
- Refrigeration and Laboratory Environment
- Three-Month Supply of Testing Materials Maintained
- Alternate Water Sources Identified

# Emergency Checklist

- Tests to be reported are prioritized
- States with same screening materials are identified

# Emergency Checklist

- Contacts identified
- MOU's established
- Plans established for compensation, specimen transport, reporting test results, on-site entry of off-site data
- Plans for temporary relocation of staff
  - In-house staff identified
  - Financial mechanisms for travel and housing

# Testing Materials Procurement

## Manufacturer/Supplier Responsibilities

- Adequate forward stocking and transportation plans established
- Plan to provide equipment to alternate site

# Backup Testing

## Laboratory Responsibilities

- Backup testing methods/plans

## Obtained documentation that supplier has -

- Adequate forward stocking
- Alternate transport plans

# Emergency Communications

- Incident Command
- Who's in Charge?
- Record Keeper
- Contacts identified
  - Suppliers
  - APHL
  - Other states

# Emergency Communications

- Call back system for in-house staff
- System tested annually
- System reviewed and updated semi-annually

# Communication Modes

- Telephone
  - Landline
  - Cell
  - Satellite
- Courier
- Computer controlled system
- Alternate systems

# MOU for NBS Emergencies

- MOU's are recommended to formalize mutual assistance agreements between states
- Two-Page Model Developed

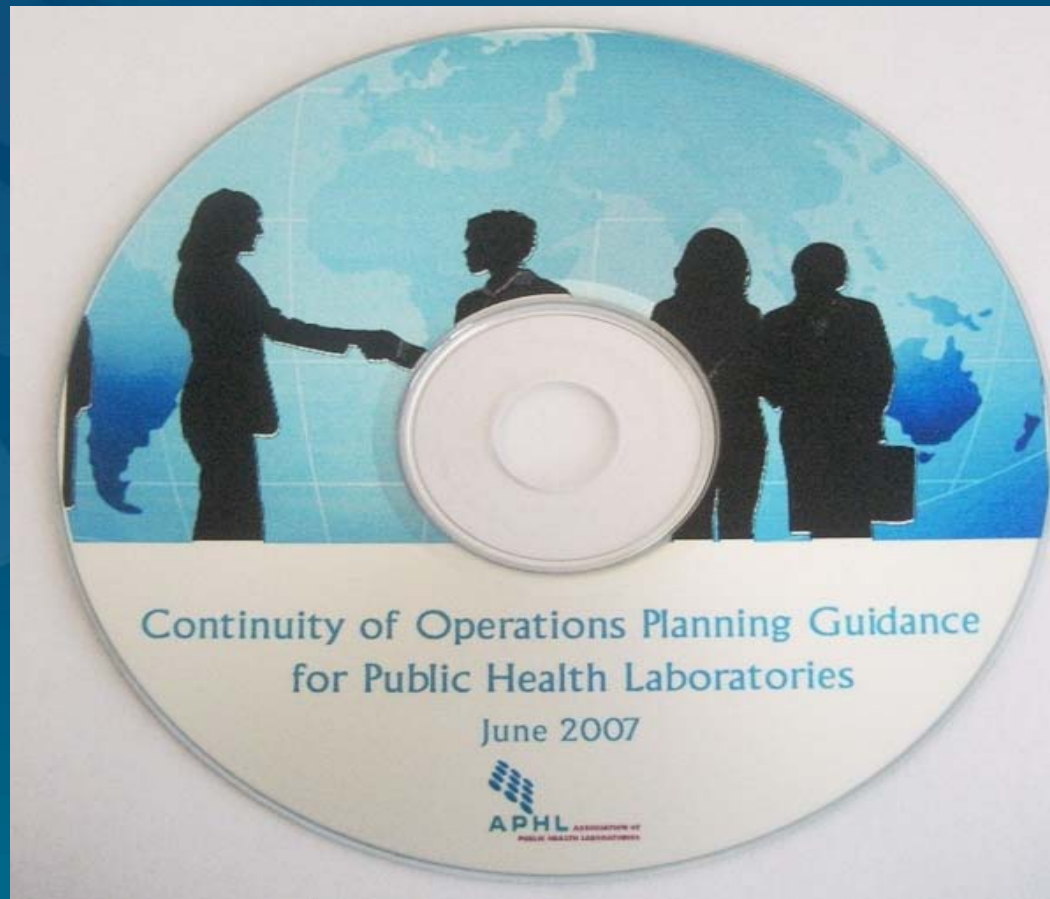
# MOU Elements

- Contact Persons
- Liability
- Terms and Termination
- Signatories

# MOU Elements

- Services
- Funding
- Specimen Transport
- Chain-of-Custody

# Continuity of Operation Planning Guidance



# Recommendations

- Every Newborn Screening Program should prepare for disaster
- Use the framework presented for preparing Newborn Screening Program Contingency plans
- Modify the framework for other laboratory testing programs