Newborn Screening: Current Status of State Newborn Screening Programs

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U.S. Newborn Screening

Mandated Disorders – October 2000

(Note: Other disorders may be offered but are not mandated)

(Note: Hemoglobinopathy screening counts as 1 screening disorder.)
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Mandated Disorders – May 2001 (Note: Other disorders may be offered but are not mandated)

(Note: Hemoglobinopathy screening counts as 1 screening disorder.)
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Mandated Disorders – March 2003

(Note: Other disorders may be offered but are not mandated)

(Note: Hemoglobinopathy screening counts as 1 screening disorder.)
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Mandated Disorders – May 2004 (Note: Other disorders may be offered but are not mandated)

(Note: Hemoglobinopathy screening counts as 1 screening disorder.)
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Mandated Disorders – October 2005
(Note: Other disorders may be offered but are not mandated)

(Note: Hemoglobinopathy screening counts as 1 screening disorder.)
Alaska

• CPT - I Cases: Currently 22 detected (all Native Alaskans)
  – Significance as yet undetermined – Began screening Oct. 2003 [about 10,000 annual births (25% Native Alaskans)]
  ~1:225 Native Alaskan Births

• Newborn Screening Advisory Committee created CF Task Force to consider issues related to adding CF screening.

Colorado

• Completed NNSGRC Program Review

• Currently planning implementation - Spring 2006
Florida

- October 1 – Began biotinidase screening statewide

Iowa

- July 18 – Began CF screening
- September 8 – Began receiving Louisiana NBS specimens
- Has temporary staff in place to maintain testing for several months
- Participating in national public service project to retest LA babies for which testing is unsure.
Maine

- September – NBS Advisory Committee recommended including the 19 optional tests currently offered as part of the required screening panel.
- January 1, 2006 – Required tests go from 9 to 28.

Mississippi

- Hurricane Katrina – No significant outfall – Specimens tested out-of-state at Pediatrix – Courier for transport
- Contractor and State pursuing any possible missed screens and lost reports
• September - Newborn Screening Annual Review Committee (NSARC) – Recommendations to Commissioner:
  Computer system upgrade
  Upgrading training of current lab personnel
  Hiring better trained lab personnel

• Reviewing parent and professional literature as outfall from the ACMG Report.

New Jersey

Pennsylvania

• SB 901, Oct. 5, 205 – Further defines “disease” by adding testing for severe combined immunodeficiency -
  “Diseases listed by the Department …, and severe combined immunodeficiency (SCID).”
Rhode Island

- Preparing for Regulatory Hearing prior to expand to ACMG recommended core panel.
- Expansion to 29 core disorders anticipated July 2006 (currently only MCAD and amino acids)

South Carolina

- Initiated expanded data reporting system
- Long-term goal is Internet Access by primary care providers
October 17, 2005 – Board of Health gave approval to file rule to add CF and to begin process of evaluating 16 conditions for inclusion in screening panel – remainder of “ACMG 29”

February 2006 – Projected date for finalizing addition of CF.

Partner meetings to address issues to be included in potential RFP – Must be 10% lower than in-house cost for acceptance

Must respond to NNSGRC Review and perform cost analysis (March 2006)

Anticipated start of expanded testing – Oct. 2006

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February 2006 – Projected date for finalizing addition of CF.
U.S. Newborn Screening

Conditions Required or Universally Offered – October 2005

(Conditions available as an option to selected population are not counted)
Hurricane Katrina – Louisiana/Mississippi
Hurricane Katrina – New Orleans, Louisiana

Water Line – 2 ft. high on building housing New Orleans NBS laboratory and surrounding buildings. 5 ft. of water in basement took weeks to pump out.
Newborn Screening – Katrina

Timeline

August 29  |  Katrina hits New Orleans
August 31  |  Louisiana NBS seeks help
September 1 |  EMAC, “Interstate Mutual Aid Request” from Louisiana
September 2 |  Iowa software demonstrated on Web
September 3-5 |  Labor Day weekend
September 6  |  Iowa given NBS mission
September 8  |  Iowa receives first samples
Newborn Screening – Katrina

• EMAC, the Emergency Management Assistance Compact, is a congressionally ratified organization that provides form and structure to 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.

• EMAC is administered by the National Emergency Management Association (NEMA) [http://www.nemaweb.org]
Newborn Screening – Katrina

Operational Issues

• Merging state systems
  • Test menu
  • Specimen timing
  • Data collection
  • Data reporting
  • Follow-up
Operational Issues

- Increased testing capacity
  - Test
    - New facility – adequate space – occupied 3 months
    - Redeploy, hire technical and data entry staff
    - MS-MS devices – two available
    - Punch devices – additional punch provided by Perkin Elmer
    - Reagents - Perkin Elmer
  - Data entry
    - Scan collection card into information system
      - Remote data entry with side-by-side system
      - Patient demographics on left entered into web entry form on right
    - Even the Director entered data the first week
Newborn Screening – Katrina

Dr. Mary Gilchrist, Iowa Public Health Laboratory Director
Assisting in data entry for Louisiana NBS specimens
Implementation Issues

- APHL facilitated linking activities
- Multiple offers for assistance including private screening providers and reagent/instrument manufacturers
- EMAC used for public health emergency response
- Major issues: Screening panel - Reporting
- Confirmatory laboratories – Miami (Gal), Maryland (PKU), D.C. (other metabolics)
- One month of screening (9/8-10/7)
  - Reported results on 4,923 newborns
  - Reported out 35 presumptive positives – 1 diagnosed PKU
Other Issues

• Payment for screening activities not yet resolved – assumption is that EMAC will assist – reagents donated for 3 month period

• Pharmacy for distribution of metabolic formula – relocated from New Orleans to another city – payment issues to be resolved (procurement rules, etc.)

• Follow-up staff – 1 temporarily hosed in Mississippi DOH, others in Baton Rouge

• Hospitals slowly reopening – some specimens held, some lost, patients displaced

• Ongoing effort to locate unscreened newborns – CDC, LA DOH, IA DOH, PSAs, toll-free call in available