What's New With the Newborn Screening Clearinghouse (NBSC)?

May 19, 2010

Natasha Bonhomme
Genetic Alliance

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Vision

- Connect parents and healthcare providers with resources and information
- Improve understanding and informed decision-making
- Facilitate information sharing
- Enable data transparency, integrated tools, technologies and education, and provide a basis for follow-up
- Provide information on federal funding for NBS
- Understand the interface between public health and the healthcare deliver system

What the Act Requires

- Centralize and online
- Research-based information
- Information on each state
- Interactive forum
- Data
- Dissemination

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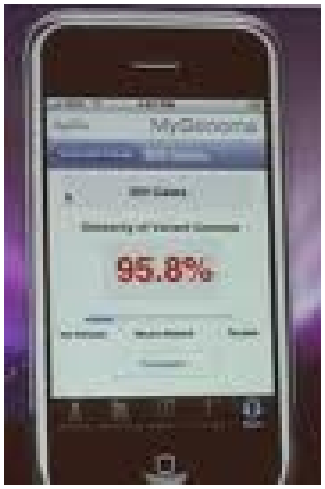
APHL | Association of Public Health Laboratories

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration
Maternal and Child Health Bureau



CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

APHA American Public Health Association

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NBS Clearinghouse Overarching Issues

- Prioritizing information / quality filters
- Roles: consumers, primary care providers
- Public Education / Interactive components
- Inclusion of international perspectives, issues

Activities for Year 1

- Beta site (October 2009 • NBSC 0.9)
- Presentation to Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (January 2010)
- Construction of the NBSC 1.0, 2.0 and 2.x
- Assisting in community engagement around data issues

Work Done on Behalf of the Clearinghouse

- Workshop during Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium (May 2010)
  - State programs serving state needs vs. national health agenda
  - Tsunami of HIT infrastructure
  - Resources need to be carefully evaluated and capitalized upon
  - Care coordination most critical to states, and complex across systems

The Beta website

- www.nbsclearinghouse.org