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

May 19, 2010

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Genetic Alliance

Posted in the Resource Repository at:
http://www.resourcerepository.org/documents/1951/what’snewwiththenewbornscreeningclearinghouse(nbsc)?
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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
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